Final Report - R21 HS020316-01
NICU-2-HOME: Using HIT to Support Parents of NICU Graduates Transitioning Home

Study Team

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Abstract

Purpose. This study designed, implemented, and evaluated the feasibility of a novel health IT intervention, NICU-2-Home, using qualitative methods that will support both mothers and fathers of Very Low Birth Weight (VLBW) Neonatal Intensive Care Unit (NICU) graduates as they transition to home.

Scope. The use of technology to communicate with parents while in the NICU is an area of research that had yet to be explored, lacking predominantly on the information and communication technology strategies during the transition to home. NICU-2-HOME, a parent-centered technology service was developed in order to address this knowledge gap.

Methods. Qualitative methods were used to develop the smartphone app and identify parental concerns. A feasibility RCT evaluated the effect of the app with all enrolled parents completing a competence assessment two weeks prior, one day prior, and two weeks following their VLBW infant's discharge from the NICU. Half were given randomized to receive a smartphone with the NICU-2-HOME application at baseline and half were randomized to standard care.

Results. 25 parents completed the qualitative interviews and a number of concerns emerged and were incorporated in the final app. Ninety different parents then completed the RCT. Both intervention and control groups had equal self-efficacy scores at baseline with a moderate increase in parental sense of competence at the time of, and following, their child's discharge from the NICU ($p = 0.048$) for the intervention group. Increased usage levels of the application were associated with an improved parental sense of competence, preparedness for discharge and length of stay.

Conclusion. As VLBW infants survive to discharge, bolstering parents' self-efficacy and competence using a smartphone intervention is one method to support primary caregivers of these infants, which may ultimately improve VLBW infant outcomes indirectly by improving parental functioning.

Keywords: Technology Use; User-Centered Design; NICU; VLBW: Health IT; mHealth

A. Purpose

The overall objective of the proposed work was to develop NICU-2-Home, a patient-and caregiver-centered mobile application service that will provide an informational and communication lifeline for parents of VLBW infants as they transition from the NICU to their homes. Based on the theory of self-efficacy[1, 2,] it is essential for parents of VLBW infants to feel competent in their ability to care for their high-risk infants in order to be successful in the parenting role[3]. Having appropriate information and communication is known to help parents feel confident in caring for their VLBW infants [4-6]. Interfacing appropriate clinical, educational, and medical history information formed the foundation of NICU-2-Home. NICU-2-Home attempted to achieve 4 "rights": delivering the "right" information at the "right" time to the "right" person via the "right" medium.

A.1. Objectives

- To design a novel health IT intervention, NICU-2-Home, using qualitative methods that will support both mothers and fathers of Very Low Birth Weight (VLBW) Neonatal Intensive Care Unit (NICU) graduates as they transition to home.
- To implement NICU-2-Home in the NICU and during the transition to home.
- To conduct a feasibility study with randomization in the NICU to test the ability of NICU-2-Home to:
    - (a) Improve mothers' and fathers' self-efficacy and confidence in caring for their VLBW infants;
    - (b) Decrease mothers' and fathers' stress as measured by self-report and salivary cortisol sampling; and
    - (c) Enhance mothers' and fathers' involvement as measured using standardized tools with their VLBW infants as compared to controls.

B. Scope (Background, Context, Settings, Participants, Incidence, Prevalence)

B.1. Background

Premature birth occurs in almost 12% of births[7] with Very Low Birth Weight infants (VLBW, birth weight <1500g) comprising 18% of the premature low births[8]. VLBW infants approach the limits of viability and their survival becomes directly proportional to gestational age and birth weight[9], with parents providing all care after successful discharge. Among neonates, VLBW infants have the longest average length of hospital stay as well as the highest rates of morbidity and re-hospitalization in the first year[10, 11].

While the experiences of parents of VLBW infants admitted to the NICU have been studied[12-15], the specific needs of parents transitioning home from the NICU have received less attention[16, 17]. Only a handful of studies have focused on this transition from the NICU to home, reporting parents must adapt to their new role and a significant number of parents experience two or more barriers to care within two weeks after discharge[18]. Despite efforts by NICU staff and with the American Academy of Pediatrics (AAP) policy statement on the importance of involving parents in care and education from admission through to discharge[20], parents desire more information than is provided to them and frequently feel unprepared for discharge[21-24].

Technology is one way to support parents making the transition from the NICU to home. In 2014, Pew Research Internet Project reports 90% of adults have a cellphone and among those of child-rearing ages 18-49, 78% have a smartphone.

B.2. Context

A smartphone application designed around the concerns of this population that provides information, education, monitoring of their infant's progress toward discharge, and encourages parental support of one another may be an effective way to support parents during this stressful transition. Such an application can accommodate general information as well as tailored information for specific parental or infant concerns that is readily available. While many applications have been created since this project began and are available for general newborn care, few were created with the NICU infant in mind and none have been scientifically evaluated for their efficacy in providing support to parents.

The theoretical basis of NICU-2-Home is Bandura's self-efficacy theory, which describes the belief in one's capabilities to organize and execute the course of action required to manage prospective situations[25]. The self-efficacy components include mastery experience, vicarious experience, social persuasion, and physiological states. When applied to parenting, self-efficacy theory suggests that stronger parenting self-efficacy would result in an improved ability for parents to care for their VLBW NICU infants[25, 26]. This study reports the outcome of a trial where we hypothesized that the NICU-2-Home app would lead to improved parenting self-efficacy for parents during the transition to home after a NICU stay with their VLBW infants compared to controls.

B.3. Setting

Participants were parents of VLBW infants in the Chicago area.

B.4. Participants

Inclusion criteria for the preliminary qualitative interviews: 1.) English-speaking 2.) 18 years of age or older 3.) parent of at least one VLBW infant (weighing less than 1500 grams) who survived to discharge from the NICU and transitioned to their home.

Inclusion criteria for the randomized controlled study: 1.) English-speaking 2.) 18 years of age or older 3.) parent of at least one VLBW infant (weighing less than 1500 grams) who survived. Parents of eligible patients were eligible for the study if they demonstrated sufficient English ability to understand and sign the informed consent form, complete assessments at all time-points, and had sufficient cognitive and motor abilities to operate the smart phone device. Recruitment began when the infant transitioned from isolette into open crib (~34 weeks of age).

C. Methods (Study Design, Data Sources/Collection, Interventions, Measures, Limitations)

C.1. Study Design

Preliminary semi-structured qualitative interviews were initially conducted in a smaller focus group to examine the utilization of information and communication technology (ICT), as well as concerns and coping mechanisms of parents whose child was making the transition from the NICU to their home. A semi-structured interview protocol designed by the researchers relied on a clinically relevant timeline framework for parental concerns during the transition home. The interview protocol used the timeline to anchor parents to three time points along the transition to home: (a) preparing for going home, (b) arriving home in the first couple of days, and (c) being at home the first few weeks. The interview was conducted by phone with each participant in his or her residence and lasted from thirty to sixty minutes. One or both parents could participate and to facilitate father inclusion, each parent was contacted separately to assess interest in the study. The interview initiated with probing, open-ended questions, and interviewers were allowed to bring up new questions and probe further into responses provided by the interviewee.

For the randomized study, VLBW parents who met eligibility criteria and agreed to participate in the study were consented and a baseline questionnaire was completed in the clinic. Parents were subsequently randomized into either two groups, usual care, serving as the control group, or usual care plus a smartphone, serving as the intervention group. Randomization was administered with a sealed and numbered assignment envelop whose contents were blind to the research team. To ensure a 1:1 ratio, randomization assignment permutations of 25 blocks with four levels were generated with levels 1 & 3 assigned to intervention and levels 2 & 4 to control. The care team was not told (a) parents' decision to participate nor b) their assigned group.

Research staff reviewed the electronic medical record and contacted the NICU care team to check infant's clinical course. Potentially eligible parents were then approached; in some cases, it was not until face-to-face discussions that ineligibility was ascertained. Parents were not approached if they were ineligible, if the care team deferred involvement, or the infant was advancing too quickly thereby limiting the intervention time.

Each parent in the intervention group was given a smartphone with the NICU-2-Home application, mobile phone service, and a data plan. Motorola Atrix2 smartphones were the mobile hardware used.

We collected saliva samples from all enrolled parents to measure the stress hormone, cortisol. Examination of physiological stress was necessary for understanding how stress gets "under the skin" and affects the body. Cortisol, the final product of the hypothalamic-pituitary-adrenal (HPA) axis, one of the body's two stress systems, is a steroid hormone indicating a physiological response to stressful situations. Healthy individuals have significant diurnal variation in cortisol levels, with peak levels upon waking, a gradual decline across the day, then reaching a nighttime nadir. Variation in the cortisol diurnal rhythm is associated with a variety of poor health outcomes; cumulative stress leading to allostatic load leads to HPA axis dysregulation, which prevents negative feedback in cortisol levels and disruption in diurnal variations, which further leads to dysregulation among a variety of physiological systems such as immune, metabolic, and cardiovascular processes. Prototypical HPA axis functioning is responsive to social contexts, including positive social relationships, which are beneficial for health and stress reduction.

C.2. Data Sources/Collection

Preliminary qualitative interviews were audio-recorded and subsequently transcribed verbatim for data analysis.

Each parent in the intervention group created a unique account and their phones are linked via email address in order to share updates in each feature (**C.1.**). NICU-2-Home use was monitored and reported in time-stamped server logs. Parents were oriented to the app and required to demonstrate minimal understanding by creating a single, synchronized profile for their infant, accessing each of the four service sections, and sending one Mood Tracker entry. Only the NICU-2-Home application services were monitored; parents could use their smartphones for personal use.

The NICU-2-Home service was hosted in a web server using Apache Tomcat web server with a combination of Java servlet and MySQL on the server-side. The access to the server was protected using HTTPS secure connection that provides encrypted communication to prevent eavesdropping and to securely identify communications between the server and the client. The Android platform was an "open source" operating system for mobile devices and includes additional middleware and key applications such as calendar and media players. The Android platform provided significant advantages for the NICU-2-Home system implementation including enhanced security architecture, compatibility with multi-device messaging service, and customizability of the home screen. For data security, the application was designed such that it will erase all the local data from the phone as soon as the participant signs out of the application.

C.3. Intervention

The qualitative findings defined the content of the NICU-2-Home app. NICU-2-Home had static content and interactive features and was designed based on findings of the needs of VLBW parents who had transitioned home[27]. The four main features include: 1.) Passport-2-Home: a self-guiding discharge checklist; 2.) Education Center: curated, multimedia educational information on NICU infant care; 3.) Baby Connect©: a commercially available app for tracking activities of daily living; and 4.) Mood Tracker: synchronized updates of parents current mood. (**Figure 1**)

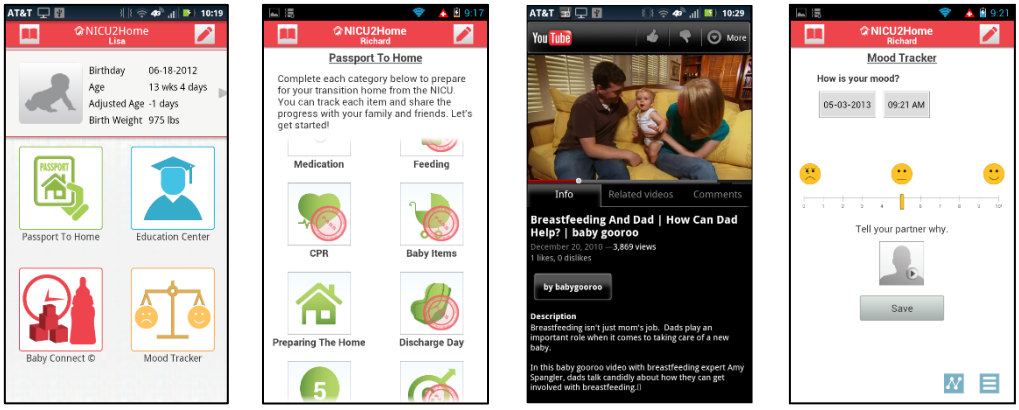


Figure 1. Screenshots of NICU-2-HOME, a smartphone app to support VLBW parents

Utilizing the main features listed in above, the NICU-2-Home application was a tool for the intervention group that provided: 1) guided learning on the discharge process, 2) multi-media based, curated educational materials on NICU infants' care, and 3) utility tools to track the baby's daily activities and parent's emotional state. NICU-2-HOME was comprised of mobile clients and a web server. The mobile clients were built on the android platform to enable parents of NICU infants to access the NICU-2-HOME services.

C.4. Measures

Parents involved in the qualitative study were engaged in an open-ended, interview with probing questions regarding their needs, concerns, and coping mechanisms as they faced discharge and the transition home from the NICU.

Parents in the RCT were given a number of surveys at various key clinical time points in order to assess the effect of the intervention. The measures, clinical and technological events, and timeline for collection are shown in **Figure 2**. All parents completed a 17-item *Parenting Sense of Competence Scale* (PSOC), a self-report scale that assessed satisfaction of parenting and parental self-efficacy[28, 29], was measured at baseline (T-14), two weeks prior to their child's discharge from the NICU, one day prior to discharge (T-1), and two weeks after discharge (T+14). Parents completed the surveys independently of each other.

	Two weeks prior to discharge (T-14)	The day prior to discharge (T-1)	Discharge (T0)	The day after discharge (T+1)	Five days after discharge (T +5)	Two weeks after discharge (T+14)
Estimated gestational age	• 36 weeks		• 38 weeks			• 40 weeks
Clinical event	• Open crib		• Discharge			• EDC
Technology event	• Smartphone • App use • Mood Track					
Data collection event	• Recruitment • Randomized • Consent • Demo. survey	• Survey • Saliva collection		• Survey • Saliva collection	• Survey • Saliva collection	• Survey • Saliva collection

Figure 2 Study design and data collection points

Several socio-demographic characteristics were collected and used in the analyses: Age and gender (referent: male) were as reported. Gestational age (weeks) and birth weight (grams) were continuous variables.

Gestation number was an integer ranging from singleton (referent) to triplet. Dichotomous variables included marital status (referent: not married), education (referent: not-college educated), employment (referent: not employed), and income (referent: earning >$60,000/year). Nominal/class variables included race (referent: White) and insurance type (referent: public). Other variables necessary to control for in our analyses included hours of sleep (which can affect HPA axis and cortisol), breastfeeding status, and medication use. To control for postnatal depression we administered the Edinburgh Postnatal Depression Scale (EPDS), a 10 item self-report questionnaire Identifies patients at risk for perinatal depression. The EPDS has been used to study postnatal depression in mothers and fathers in the NICU[31]

For the imputation process, two auxiliary variables were used 1) a Pew general technology attitudes summed score[30] and 2) a technology for parenting attitudes summed score (adapted by inserting "…for parenting" in each question). Summed scores provided a use of technology confidence index; higher scores reflect greater confidence in technology.

Parents' NICU-2-Home use was measured using constructed user level variables based on the total counts of app daily usage data. To see within- and between-level differences in use and account for difference in length-of-stay, we constructed variables from two different sources. Total average count in NICU measured the total average number of times all services were used within a given day until discharge. The mean of this variable provided our three user groups. Non-users—those assigned control-- were referent. Total study average was also measured and is the mean total uses per day—that is, the rate of usage—for the entire study period.

Salivary cortisol levels, a biomarker of physiological stress, was collected one day prior to their child's discharge and two weeks following. Measurement of wakeup, 30 minutes post wake-up, and evening levels of cortisol provided both a more accurate estimate of average cortisol levels across the day, as well as the opportunity to examine the slope of the diurnal cortisol curve and the cortisol response to awakening, each of which has been associated with health outcomes.

C.5. Limitations

A major limitation is the fact that this study focused solely on the transition home for parents of VLBW infants only and at one institution. The usefulness, feasibility, or efficaciousness over a different time period, in a different population or another institution is unknown. Further, parents in the intervention group who received a smartphone may have used it in other circumstances, aside from utilizing the NICU-2-Home application, to boost self-efficacy, which impacts PSOC findings. However, 92% of the intervention group already owned smartphones so it is unlikely the additional smartphone hinders results.

D. Results (Principal Findings, Outcomes, Discussion, Conclusions, Significance, Implications)

D.1. Principal Findings

D.1.a. Sample

Qualitative Study

Preliminary qualitative interviews included fifteen mothers (age = 32±5 years) and ten fathers (age = 35±5 years) of sixteen VLBW NICU graduates who had been discharged from the NICU to home two to three months prior to the interview (**Table 1**). Both parents in one household were allowed to participate in the study if they wanted. The majority of participants (n=21, 84%) were first time parents. The average gestational age of infants was 29.5 weeks, and the infants stayed in the NICU an average of 58.38 days. With regard to education level, 20% (n=5) of parents have advanced degrees, 44% (n=11) have college degrees, 28% (n=7) have some college or technical training, and 8% (n=8) have high school graduate or equivalent.

RCT study

Ninety VLBW parents who met eligibility criteria were randomized to usual care (n=44) or usual care plus a smartphone with NICU-2-Home (n=46). The survey completion rate was: 95% at baseline-controls and 87% baseline-intervention (**Figure 3**). Biomarker return rate was 83% overall (71/86), with 86% for women and 80% for men. Follow-up completion rates at T+14 were 70.4% and 69.6%, for controls and intervention, respectively.

Randomization created two similar groups, with differences only in age (p=0.019) and race (p = 0.015) (**Table 2**). Most parents were married, educated through college, and had private insurance. Infants' were mostly singletons with 29.69 weeks average gestational age and 1224g average birth weight. NICU-2-Home app use fell into three categories: above average users (> 75th percentile; mean usage = 9.7 times/day, n = 10), average users (25th – 75th percentile; mean usage = 3.8 time/day, n = 18), and below average users (<25th percentile; mean usage = 1.3 times/day, n = 10). Our study was powered to find statistically significant results with 40 participants in the two groups assuring 80% power at 0.05 to detect a moderate effect size of 0.63, for a longitudinal analysis assuming a 0.5 within-subject correlation (ICC). This sample size also assures 80% power at 0.05 to detect a PSOC score difference of 8.6% to 16.4% at pre- and post-discharge[29].

D.1.b. Qualitative Interviews with Parents

Two papers were published from the qualitative interviews with the results presented here. Four themes regarding parental use of ICT were identified through qualitative analysis.

1) Mothers were the primary information seekers, favoring parenting websites and displaying more information seeking behaviors over fathers. For example, one father depended on his partner by asking her provide a list of essential information needed for him to read:

> *"My wife did use the Internet quite a bit to find out some information and to keep us up to date as to what to do, what to look for, and what to watch for. She was the one who was in charge of the whole information, and for me I was just reading it. She was taking care of collecting all those information."*

2) Both parents were concerned with online privacy issues and mistrust in health information found on the Internet. For instance, both parents were concerned with online privacy so that they did not post detailed information on Facebook. Parents primarily posted photos and short general comments instead:

> *"I didn't really feel comfortable broadcasting all over Facebook how he [the baby] was doing. That is a personal preference, I never really updated [the Facebook] beyond just saying they are doing well or something very general. I didn't feel comfortable that people who I haven't talked to since high school know the medical status [of my baby]."*

3) Parents looked for people like themselves online. For instance, mothers looked for blogs written by other mothers in the same situation. Fathers looked for blogs written by other fathers' experiences. One father stated:

> *"I was really searching for a male response to the NICU experience and discharge. There was one twin dad's blog I just wanted to read it. On the blog he had talked about the teaser regarding in and out of the hospital with his wife's pregnancy. There was information about dealing with your own emotions and masculinity kind of neuroses."*

4) Choosing a health care provider typically fell to mothers using various ICT tools with fathers tending to rely on mothers to make a decision for choosing a pediatrician and making an appointment. One example is a father stating:

> *"My wife was pretty much a primary caretaker and I was more of the secondary caretaker at that point after the first couple of days of discharge. You've got to ask my wife on that [picking the baby's pediatrician]. Honestly, that was her choice."*

Other themes examined the difference in concerns and coping mechanisms of the mothers and fathers. These include: health information, privacy and misinformation, online social networking, learning technology, and choosing a health care provider.

In our second paper we focused on VLBW parents' concerns. Overriding concerns among parents included pervasive uncertainty, lingering medical concerns, and partner-related adjustment concerns that differed by gender. A variety of resilient coping methods during the NICU to home transition were also described.

1) "Pervasive uncertainty" was the major theme that emerged for parents and permeated nearly all aspects of their life: how they perceived their child, the presumed capabilities of their outpatient healthcare team, as well as the parents' own abilities to care for their child. One father of a 29-week female infant who had a 30 day NICU stay summarized:

> *"You know, we had been through quite a bit already, and it was like, 'Oh my gosh what if something happens? What if this and what if that?' and it's all the 'what if's?' that kind of run through your mind that you're just thinking, 'What if I do something wrong?'" These "what if's" and the fear of doing something wrong or harmful to the infant were heightened by the fact that many parents felt leaving the supervised and highly-specialized setting of the NICU seemed inherently more risky and uncertain, that "we're not in the hospital, we're first time parents…I fear doing something wrong to hurt him."*

2) Lingering NICU medical concerns would follow parents home. During the transition to home almost half of parents voiced lingering concern over feeding issues, such as spitting up, not gaining weight or poor feeding in general, and breathing issues, which were frequently lumped into "As, Bs, and Ds" (apnea, bradycardia, and desaturation in oxygen). In the case of the mother of a 32-week female infant with a NICU stay of 30 days, feeding and breathing concerns co-existed:

> *"She was still really small, I mean, weight-wise. The fact that when she was feeding, she would still have moments where she stopped breathing…that definitely, those two things really scared us."*

3) Maternal and paternal concerns differed. Mothers voiced concerns around the father's ability to balance work and family, and the "stress" and feeling of "overwhelming" that an imbalance may create for the father. In turn, fathers were more concerned about the mother's mental and physical wellbeing during the transition to home. A father of a thirty-two week infant stated:

> *"I was worried about her and you know postpartum depression. My concerns for her had a lot to do with her own personal state of mind and, is she going to be able to handle having this new baby in the house because I know how she is, the constant worry and concern."*

4) Parents enlisted a variety of methods to address the stress and uncertainty inherent in caring for a premature infant. These coping mechanisms generally evolved organically from the parents and were not part of any specific NICU training or teaching. Four major approaches were employed: a) physical activity or movement, b) shifting their mental perspective, c) reconnecting with their infant, and d) reaching out to their social support system.

D.1.c. RCT results: Parenting Sense of Competence

The sample PSOC had a baseline mean of 70.8 (range 48 – 95). Imputing the values for the roughly 25% missing outcome data for T-1 and T+14 made minimal changes to every descriptive statistic except for the skewness, which normalized for both T-1 and T+14 PSOC scores.

In the repeated measures mixed linear model, parents in the NICU-2-Home group reported improved self-efficacy scores (**Table 3**) whereby a greater level of use was positively associated with parental self-efficacy (**Figure 3**). Above average users had the greatest increase in PSOC score per session ($\beta = 6.681$, 95% CL = (0.628, 12.734), $p = 0.031$) leading to a 13-point increase over the study, an 18% improvement from baseline. Average users had the second greatest increase ($\beta = 4.321$, 95% CL = (0.226, 8.416), $p = 0.039$) of 8 points, a 12% improvement. Below average users were not statistically significantly different from non-users over each session although the estimate was slightly positive ($\beta = 1.448$, 95% CL = (-2.766, 5.663), $p = 0.498$). No baseline

differences were found among the different user levels. Of note, PSOC scores increased moderately over each session for everyone (β = 1.606, 95% CL = (0.014, 3.198), p = 0.048) suggesting discharge may slightly improved self-efficacy. College graduation was the only significant socio-demographic characteristic (β = 11.322, 95% CL = (1.577, 21.066), p = 0.023). Though the total count average overall was not statistically significant, the estimate for the total count average over each session was significant and negative. (β = -1.628, 95% CL = (-2.753, -0.502), p = 0.005); however, when controlled the overall effect was positive.

Above average users of the NICU-2-Home application felt significantly more prepared for the transition from the NICU to home compared to non-users (85.7% and 27.6% respectively), feeling "very good" about the NICU discharge preparation (p = 0.037). The controls were asked to rate the typical education material they received; their "very good" endorsement of being prepared to care for their baby was the lowest (27.6%).

D.1.d. Maternal and Paternal Biomarkers

Mothers and fathers had mostly typical diurnal cortisol rhythms, with highest levels at wakeup and lowest levels at bedtime. However, cortisol slope and wake cortisol means for men were different between NICU and home ($\bar{x}$ = -0.027, -0.018; $\bar{x}$ = 0.542, 0.452) whereas for women they were similar ($\bar{x}$ = -0.023, -0.021; $\bar{x}$ = 0.450, 0.412). Cortisol at wake + 30 and bed were similar at NICU and home for both genders. Paired t-testing revealed parents in the same family had similar cortisol levels at the home time, but lacked similar patterns while in the NICU. Specifically, fathers showed a flatter profile (lower wakeup, higher bedtime) of diurnal cortisol at home compared to in the NICU, suggesting that fathers may be experiencing higher physiological stress after the discharge home from the NICU (see **Figure 4**; βslope = 0.044, SE = 0.019, p = 0.027). A similar finding was not evident for mothers, in that mothers had diurnal profiles that were largely unchanged from NICU to home.

D.2. Outcomes: NA

D.3. Discussions

In this study we took a mixed methods approach to understanding the needs and concerns of parents of VLBW infants in order to design and test an intervention to support these parents of vulnerable infants as they transition from the NICU to home.

The five ICT themes identified in the qualitative analysis were evidence of a dynamic interplay between mothers and fathers as they use ICT to navigate their infant's NICU stay and discharge home. With fathers' help, mothers take full advantage of ICT to play a key role in caring for their infants by, for example, seeking reliable health information, educating fathers, keeping track of the infant daily activities, obtaining social support, and communicating with health care providers. Those are important issues for parents transitioning home with a medically vulnerable infant after a long stay in the NICU. Understanding and appreciating these issues may open opportunities for supporting parents of VLBW infants through ICT.

Other themes described the concerns of parents with VLBW NICU graduates during the particularly stressful time of the transition to home after prolonged stays in the NICU. Despite the fact that their infant survived admission, the long NICU stay, and was able to be discharged to home and community care, these parents describe in their own words the pervasive uncertainty around the health of their baby, their abilities to care for their baby, and the abilities of the community healthcare providers who were often new to the families.

Based on these qualitative findings, several implications emerge for designing technology support and interventions for NICU families. First, user interface designers should carefully consider incorporating gender-sensitive user interfaces to online social community websites where the majority of visitors are NICU mothers. Second, a personalized website alternative, similar to a Facebook archetype that assures privacy by allowing parents to control the level of privacy and public access is needed. Third, a blog aggregator may help NICU parents find other NICU parents' blogs widely dispersed online. Aggregators function to reduce the time and efforts needed to locate other blogs, regularly check for updates, and retrieve the updates. Further, specific aggregators

may be able to compile social websites that are specific or are written specifically for mothers or fathers. This may be next design steps.

In the randomized clinical trial, parents of VLBW infants who received the NICU-2-Home smartphone app intervention along with usual care reported improved parenting self-efficacy during the transition from the NICU, through discharge and finally being home with their infants. Parenting self-efficacy improved in a dose-dependent manner, such that the more the app was used, the greater the increase in self-efficacy. This is evidenced by an 18% improvement in PSOC (13 points) for above average users and a 12% increase (8 points) for average users, representing a nearly one standard deviation above the mean of the sample for these two groups. Clearly, for many parents in the NICU as appropriately designed smartphone app can improve their support.

Salivary cortisol levels of fathers were sustained at a higher level though out the day following NICU discharge, indicating an increase in paternal sensitivity to stress during the transition from NICU to home ($p = 0.027$) that is not evident in mothers. As little is known about parents' biomarkers and stress responses in the NICU this is an area ripe for future study.

D.4. Conclusions

Overall this study examines the needs of VLBW parents and tests a specially designed smartphone application as a novel approach to supporting parents. By grounding our study in qualitative data there are a number of conclusions to be drawn.

First, this study contributed to advancing the understanding of how mothers and fathers with VLBW NICU infants use ICT during the transition from the NICU to home. Better understanding of the two partners' needs and usage patterns in ICT is likely to help to deliver a technology intervention that accommodates both parents, leading to higher user satisfaction and technology adoption. Given a well-designed technology intervention, both parents would become better educated, potentially leading to higher confidence, improved parenting skills and knowledge, and better health outcomes for NICU infants.

Second, fathers and mothers of VLBW NICU graduates describe evolving, but often differing, concerns as they transition home, many of which can be addressed with improved discharge informational exchanges and anticipatory guidance. In addition, variations in hormone rhythms were reflected. Paternal cortisol physiology is perturbed with the transition to home, suggesting a biologic stress sensitivity for fathers only. Supporting parents during this stressful and often difficult transition may lead to decreased family stress, improved care, and better infant outcomes.

Finally, using our NICU-2-Home app is one way to bolster parents' self-efficacy in support of primary caregivers and their infants. Technology, and in particular applications, hold promise as a delivery vehicle for these necessary supports for the improved care and outcomes of vulnerable populations. More study is warranted to develop a scientific, evidence-based approach to the growing use of smartphone technology for parents.

D.5. Significance

This study was an example of a patient-level, parent-empowering, consumer-focused strategy to address the concerns of this population and their caregivers. Parents' own words about their ICT usage during the transition from the NICU to home provide valuable insights into technology-based intervention designs that accommodate gender differences. Future research should include more parents with diverse backgrounds and a more gender-related interview protocol.

Furthermore, this was one of the few studies to describe how mothers and fathers differed in their concerns for one another with mothers more worried about fathers' abilities to balance work and home effectively and fathers being concerned about mothers' mental and physical wellbeing.

Finally, this study lays the ground work for establishing scientifically the benefits of well designed studies of emerging technology for parents in the NICU.

D.6. Implications

Our findings can benefit user interface researchers and professionals to better understanding of the parents' homogeneous and heterogeneous use of ICT. In turn, this can lead to the development of more sophisticated user requirements that facilitate NICU parents' social networking, online research, communication with health care providers, tracking information, privacy and sharing of information, and decision making for the VLBW NICU infants' health.

By providing solid scientific evidence, similar interventions can be designed for the neonatal period that ultimately may result in improved child and family outcomes. Further, economies of scale are easily obtained. Once apps are designed and proven effective, many features translate to other patient populations. With the ubiquity of smartphones and a consumer and marketplace push for increased mHealth offerings, more applications will find their way into parents' hands and everyday healthcare encounters.

E. Publications

E.1. Presentations

Garfield, CF and Lee, Y. Designing an mHealth Program to Meet the Needs and Enhance Usage among Parents of Very Low Birth Weight Infants in the Neonatal Intensive Care Unit. mHealth Summit, poster presentation, Washington, DC. December 2011.

Garfield, CF, Lee, YS, Bolcki, K, Kim, HN. "Am I able to be a good parent?" Mothers' and Fathers' Concerns of VLBW NICU Graduates Transitioning Home. Pediatric Academic Society meeting, poster presentation, Boston, MA. May 2012.

Kim, H, Garfield, C., Lee, YS. Technology Usage and Change during the Transition to Home for Parents of VLBW NICU Graduates. AMIA meeting, 2012.

Lee, YS, Garfield, C., Kim, H. Self-Efficacy Theory as a Framework for Interventions That Support Parents of NICU Parents, International Conference on Pervasive Computing Technologies for Healthcare, 2012.

Lee, YS, Garfield, CF., Massey, N., Chaysinh, S. Hassan, S. NICU-2-HOME: Supporting the Transition to Home from the Neonatal Intensive Care Unit using a Mobile Application, Chicago 2011.

E.2. Publications

Garfield, CF., Lee, Y., Kim, H. "Paternal and Maternal Concerns for their Very Low Birth Weight Infants Transitioning from the NICU to Home." Journal of Perinatal and Neonatal Nursing, In Press.

Kim, H. N., Garfield, C., and Lee Y. Paternal and Maternal Information and Communication Technology Usage as Their Very Low Birth Weight Infants Transition Home from the NICU. International Journal of Human-Computer Interaction. 2014.

E.3. Submitted for Publication

Garfield, CF., Lee, Y., Kim, H. A Smartphone Application to Support Parents of Very Low Birth Weight Infants Transitioning Home: A Randomized Controlled Trial.

Garfield, CF., Lee, Y., Kim, H. Stress in the NICU: Maternal and Paternal Biomarkers in Parents of VLBW Infants Transitioning From Hospital to Home.

Figure 3: CONSORT Participant Flow Diagram

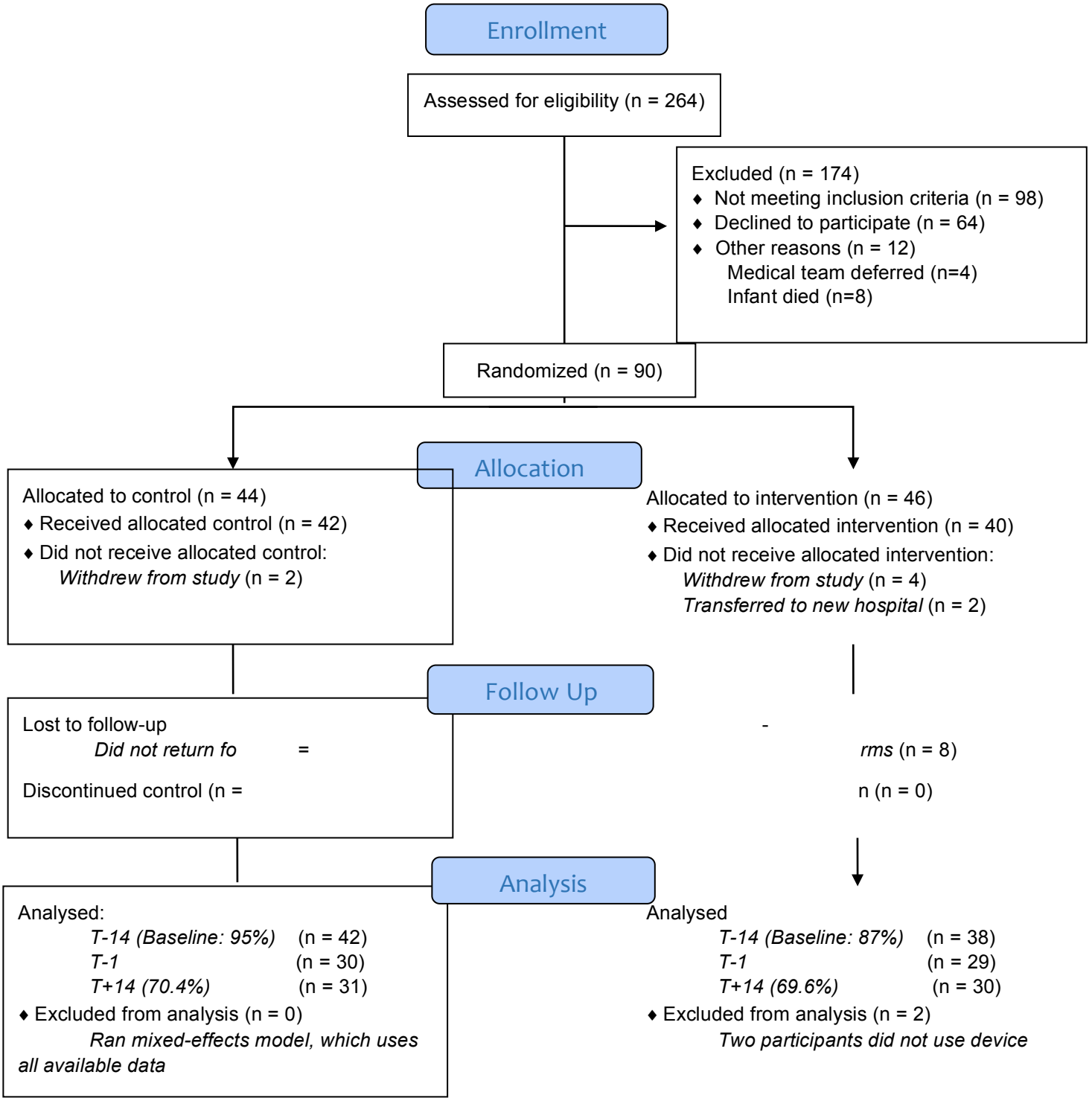


Table 1. Parent and infant characteristics for qualitative study.

Respondent Characteristics*	N=25 (%)	Mothers=15 N (%)	Fathers=10 N (%)
Age, years	31	30	32
Race/Ethnicity			
White, non-Hispanic	16 (65)	7 (47)	9 (90)
Black, non-Hispanic	3 (12)	3 (20)	0 (0)
Hispanic	5 (20)	4 (27)	1 (10)
Other	1 (4)	1 (7)	0 (0)
Education Level			
High school graduate or equivalent	2 (8)	2 (13)	0 (0)
Some college or technical training	7 (28)	6 (40)	1 (10)
College degree	11 (44)	3 (20)	8 (80)
Advanced Degree	5 (20)	4 (27)	1 (10)
Household Income			
< $20 000	5 (20)	5 (33)	0 (0)
$20 000 - $39 999	3 (12)	2 (13)	1 (10)
$40 000 -$59 999	1 (4)	0 (0)	1 (10)
$60 000 - $79 999	4 (16)	2 (13)	2 (20)
≥ $80 000	12 (48)	6 (40)	6 (60)
Marital Status			
Married	22 (88)	12 (80)	10 (100)
Not married, in romantic relationship	1 (4)	1 (7)	0 (0)
Not married, cohabiting	2 (8)	2 (13)	0 (0)
First Time Parent	21 (84)	12 (80)	9 (90)
Parent of Twins	16 (34)	9 (60)	7 (70)
Infant Gestational Age, weeks, avg	29.38		
Infant Length of Stay in NICU, days, avg	58.38		

* Sums may not equal 100% due to rounding.

Table 2. Sociodemographic Characteristics for Randomized Control Trial.

Characteristic	Total (N = 82)	Control (N = 42)	NICU-2-Home (N = 40)	p-value
PARENTS				
Age	33.7 (5.80)	35.2 (5.12)	32.2 (6.54)	0.019
Female	41 (50.0%)	21 (50.0%)	20 (50.0%)	0.912
Race				0.015
White	54 (65.9%)	35 (79.6%)	19 (47.5%)	
Black	13 (15.6%)	5 (11.9%)	8 (20.0%)	
Asian	6 (7.3%)	0 (0.0%)	6 (15.0%)	
Hispanic, Latino	9 (10.9%)	2 (4.8%)	7 (17.5%)	
Gestation Number[2]				0.508
Singlton	29 (70.7%)	15 (71.4%)	14 (70.0%)	
Twins	11 (26.8%)	6 (28.6%)	5 (25.0%)	
Triplets	1 (2.5%)	0 (0.0%)	1 (5.0%)	
Marital Status[1,2]				0.923
Married	38 (92.7%)	20 (95.2%)	18 (90.0%)	
Cohabiting	2 (4.8%)	1 (4.8%)	1 (5.0%)	
Other	1 (2.4%)	0 (0.0%)	1 (5.0%)	
Education				0.183
Through HS	4 (4.9%)	1 (2.4%)	3 (7.5%)	
Through College	47 (57.3%)	22 (52.4%)	25 (62.5%)	
Advanced Degree	31 (37.8%)	19 (45.2%)	12 (30.0%)	
Employed	67 (81.7%)	35 (83.3%)	32 (80.0%)	0.696
Household Income[1,2]				0.916
< $60k	7 (17.1%)	3 (14.3%)	4 (20.0%)	
≥ $60k	34 (82.9%)	18 (85.7%)	16 (80.0%)	
Insurance Type[1]				0.522
Private	68 (82.9%)	36 (85.7%)	32 (80.0%)	
None	1 (1.2%)	0 (0.0%)	1 (2.5%)	
Other	13 (15.8%)	6 (14.3%)	7 (17.5%)	
INFANTS				
Gestational Age, weeks	29.68 (2.55)	30.0 (2.74)	29.4 (2.44)	0.276
Birth weight, grams	1224.16 (308.21)	1170.24 (315.35)	1283.24 (302.90)	0.094
Length of NICU stay	62.18 (37.49)	59.64 (43.66)	64.70 (30.58)	0.582

Female	27 (49.1%)	13 (48.1%)	14 (51.9%)	0.993

[1] = categories were collapsed
[2] = frequencies given at household level

Table 3. Repeated Measures Mixed Linear Model Results for Parenting Sense of Competence Scores.

Independent Variable	Estimate	SE	t-value (df = 169)	p-value	95% CL
Intercept	87.7052	14.3174	6.13	.	.
Session‡	1.606	0.8065	1.99	0.0481	(0.014, 3.198)
Above Average User	-1.6791	7.9639	-0.21	0.8333	(-17.401, 14.042)
Average User	-4.148	5.243	-0.79	0.4300	(-14.498, 6.202)
Below Average User	-0.9644	5.329	-0.18	0.8566	(-11.485, 9.556)
Total Count Average	1.0333	1.4574	0.71	0.4793	(-1.844, 3.910)
Session*Above Average User‡	6.6805	3.0662	2.18	0.0307	(0.628, 12.734)
Session*Average User‡	4.3211	2.0743	2.08	0.0387	(0.226, 8.416)
Session*Below Average User	1.4488	2.1346	0.68	0.4982	(-2.766, 5.663)
Session*Total Count Average‡	-1.6278	0.5701	-2.86	0.0048	(-2.753, -0.502)
Female	0.6053	2.176	0.28	0.7812	(-3.690, 4.901)
Age	-0.2342	0.1929	-1.21	0.2264	(-0.615, 0.147)
Gestational Age	-0.3755	0.3852	-0.97	0.3310	(-1.136, 0.385)
Asian	1.7427	4.1149	0.42	0.6725	(-6.381, 9.866)
Black	4.1063	3.9424	1.04	0.2991	(-3.677, 11.889)
Hispanic, Latino	5.6325	4.493	1.25	0.2117	(-3.237, 14.502)
Singleton	-1.8677	2.3453	-0.8	0.4270	(-6.498, 2.762)
Married	-6.8428	4.8509	-1.41	0.1602	(-16.419, 2.734)
College Graduate‡	11.3216	4.9361	2.29	0.0230	(1.577, 21.066)
Employed	-3.7784	2.6381	-1.43	0.1539	(-8.986, 1.429)
Income < $60k	3.9113	5.4957	0.71	0.4776	(-6.938, 14.760)
No Insurance	-0.00886	10.6596	0.01	0.9993	(-21.052, 21.034)
Other Type Insurance	-5.1282	9.5232	-0.54	0.5909	(-23.928, 13.672)
Private Insurance	-1.0639	3.9908	-0.27	0.7901	(-8.942, 6.814)

‡ = $p \leq 0.05$

Figure 3. PSOC Scores of Enrolled Parents Over 4 Weeks

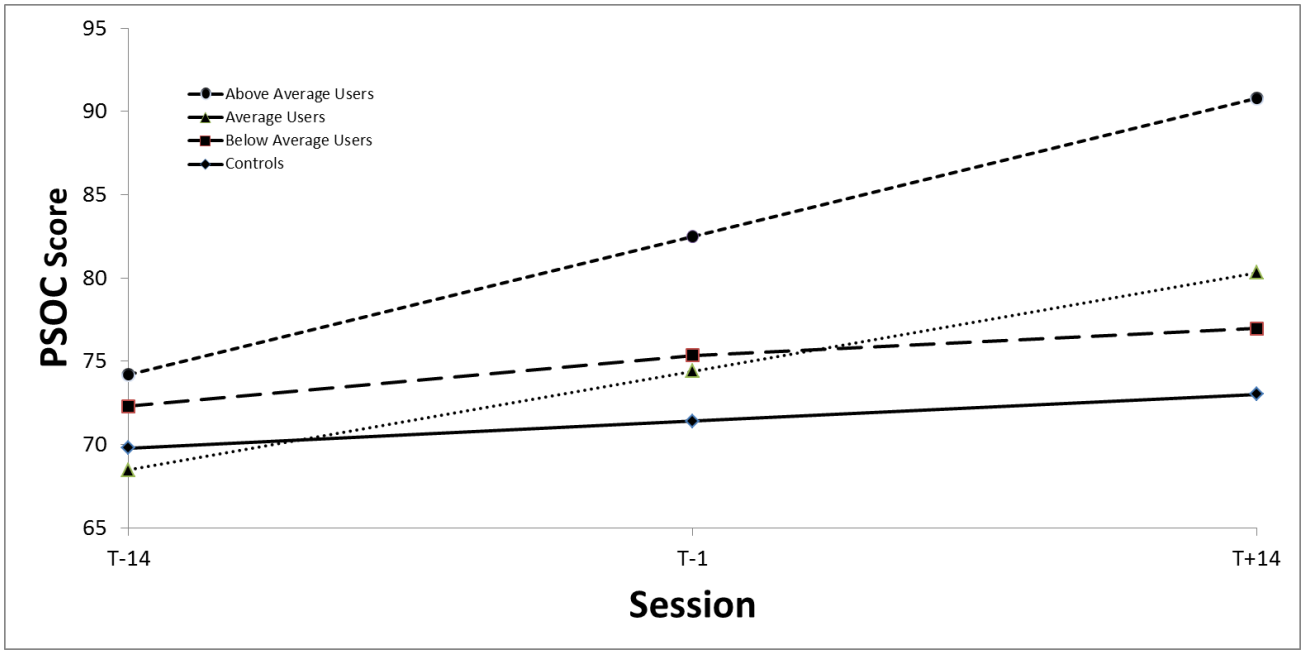
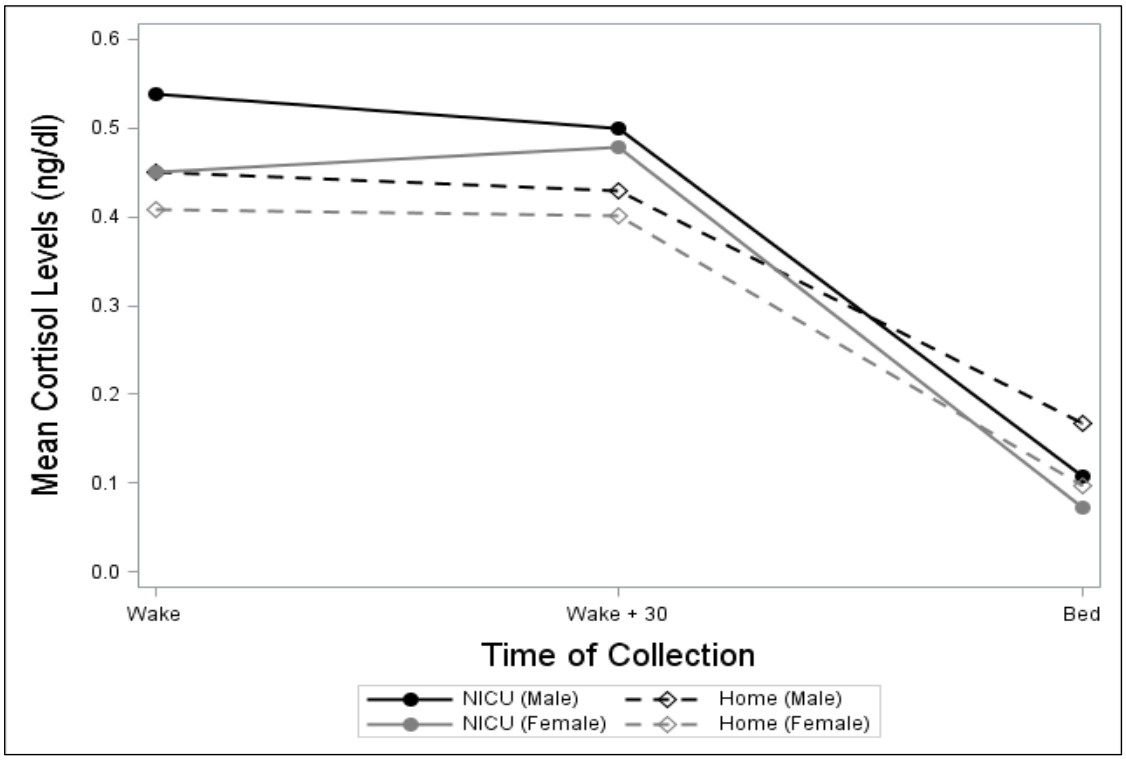


Figure 4. Mean Cortisol Concentrations as a Function of Time



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